The ethics of forced feeding in anorexia nervosa

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Guidelines for withholding forced nutrition and hydration have applied largely to patients who are terminally ill[1] — who, in Ramsey's words,[2] are already "in the article of death" — and, more recently, to those who exhibit marked incompetence, such as the demented elderly.[3-6]

Patients in the advanced stages of anorexia nervosa are more difficult to categorize. Their competence may be subtly impaired,[7] and although their lack of nutrition may be life-threatening they are not thought of as terminally ill. As a result they normally receive some form of involuntary feeding.[8-10]

We present a case in which a patient with anorexia nervosa was not force-fed and died shortly afterward. Although in some ways an exceptional case it leads us to two general conclusions. First, our standards for making decisions on behalf of incompetent patients are not easily applied to patients with anorexia nervosa. Second, "difficult and burdensome" patients, such as those who vigorously resist strenuous efforts to prevent them from dying, can arouse powerful negative feelings in caregivers. These feelings can affect judgement about life-saving care and require exploration before such care is withheld.

Case report

A 22-year-old woman with an 8-year history of anorexia nervosa was admitted to hospital stuporous and in a state of cardiovascular collapse. She appeared cachectic. She was 158 cm tall and weighed 24 kg. Her pulse rate was 140 beats/min and her blood pressure barely palpable at 88 mm Hg. The serum glucose level was 0 mmol/L and the serum urea level 24 mmol/L. Intravenous glucose infusion was started. She roused herself long enough to pull out the infusion line and then lapsed back into unconsciousness.

The central clinical question faced by the treatment team was whether, in the absence of access to a peripheral site, more aggressive forms of nutritional support should be provided.

The patient had spent almost all of the previous 8 years in hospital, and every known form of therapy — physical, psychodynamic, behavioural and family — had been tried. Despite frequent force-feeding her weight gain was always ephemeral. Two years earlier she had been admitted to a specialized anorexia unit for 9 months as an involuntary patient. Although by the time of discharge she was at her target weight of 46 kg she had been considered by the staff to be their most difficult patient. When the patient presented to our family practice clinic 1 month later she weighed 40 kg and said that she was aiming for 36 kg, below which she knew she would "get in trouble."

Several months later the patient's weight dropped from 35 to 26 kg. In a state of physical collapse and pleading for help she was admitted for refeeding. During nasogastric feeding she struggled increasingly against receiving care, biting or pulling out her tube, surreptitiously discarding food, exercising incessantly and trying to leave the hospital. Still below 30 kg she was certified as an involuntary

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patient and placed in body restraints. This escalated the struggles. She continued to resist every effort directed at weight gain and in the process created havoc: patients left the ward, and nurses did not turn up for their shifts. The nursing staff finally demanded that she leave the ward, as they could no longer tolerate the burden of her care. She was discharged 4 months after admission at a weight of 32 kg.

In the subsequent months the patient was admitted several times because of dehydration. As an outpatient she neither ate nor drank, viewing even water as having "too many calories." As an inpatient she renewed the former battles, although at times she acceded to the use of restraints to prevent herself from pulling out the nasogastric tube. At a family conference it was agreed that she would be admitted to reverse collapse and not for weight gain.

Finally, the patient was admitted in the state already described. The Ethics Committee, the patient's parents and her physicians discussed the situation. In the absence of other accessible peripheral venous sites they decided not to start further aggressive nutritional treatment, such as central venous infusion or gastrostomy. The patient died quietly the next day in the presence of her parents.

Discussion

This case raises a number of questions: Was the patient competent? Should her wish not to be fed have been respected? Would it have been medically appropriate to impose nutrition yet again? Specifically, should invasive, involuntary feeding — for example, through a gastrostomy — have been provided? What were the benefits and burdens of feeding her at this point in her illness? Finally, how should the burden that her care imposed on others have been taken into account? Is there any moral role for the strong feelings that such difficult patients arouse in their family and the health care staff?

Principles of ethics

The standard approach to such dilemmas usually refers to the principles of ethical analysis: patient autonomy (following a competent patient's wishes), medical beneficence (helping the patient) and justice or fairness (considering the interests of all involved).[11]

This patient was not a competent adult, and so her wishes could not form the basis of her care. She was impaired cognitively and volitionally.[12] Cognitively she could rarely appreciate that her life was threatened by her thinness. Her perception of her body was severely and unshakably distorted to the end. As well, she expressed contradictory wishes about hospital admission and whether she wished to live or die. However, in the last month or so of her life the patient saw her situation as hopeless and preferred death over the suffering of permanent illness. Volitionally she was impaired, because she was unable to carry out her wishes, even her wish to put on weight. She felt compelled to exercise and to resist feedings.

Everyone involved with the patient agreed that she was not competent to make choices about her treatment. Although her wishes could not determine the care she received, as they would for a fully competent patient, they nevertheless had to figure in the final decision because of her determined resistance to treatment.

The principle of beneficence is less easy to analyse in this case. The benefits of feeding are obvious enough in anorexia. Food remains the "drug" of choice.[13] Putting on weight can improve a patient's mood and overall body image.[14,15] The burdens of forced feeding can be considerable but include discomfort, deepening of psychologic illness and curtailment of liberty. For most anorexic patients the benefits outweigh the hazards, and so obligatory feeding is started when weight loss becomes hazardous.

For this patient, however, the recurrent aggressive forced feedings incurred great cost and achieved less in terms of remitting her illness or her suffering. She had received nasogastric feeding many times, without lasting success. Total parenteral nutrition, which can be helpful in extreme anorexia,[16] requires patient cooperation to prevent sepsis, air embolism and death from line manipulation. She did not cooperate, and so parenteral nutrition was not provided.

A final suggestion had been to provide nutrition through a gastrostomy tube. Technically easy[17] this option has physiologic problems[18] and would have required that the patient be placed in restraints indefinitely. There is no literature on the use of such a technique in anorexia. Should it have been done anyway in the hope that there would some day be a breakthrough in the treatment of anorexia? When, if ever, can aggressive feeding procedures be withheld from patients starving themselves to death?

In the Astaforaff case[19] a woman imprisoned in British Columbia refused food for religious reasons. The courts did not find that there was a duty to force-feed her even though she was in danger of dying. Because the law has not spoken unequivocally on this issue are there, then, moral standards that can guide us in cases of anorexia as severe as the one we have described?

Incompetent patients

The literature on treatment decisions for in-

competent patients suggests that two standards can be used.[20] One is substituted judgement and the other best interests. Both are problematic in their application in severe anorexia.

The standard of substituted judgement may be recommended if there is clear evidence of the patient's wishes when he or she was competent — for example, a viable advance directive or durable power of attorney. This standard does not apply to severely anorexic patients, because their wishes are shifting and contradictory. Although they consistently act in a self-destructive way they do not usually do so for suicidal reasons, and so their actions are irrational.

The standard of best interests, too, is fraught with difficulty. When evidence of the patient's wishes is unreliable or nonexistent one tries to balance the potential benefits of treatment against the possible burdens.[21-23] The judgement against further forced feeding of this patient seemed to be based on such a standard. The bottom line was a reluctance to commit the patient to indefinite feeding with restraints for the sake of prolonging a life of suffering.

This weighing of harm and benefit sounds objective and balanced. However, we are unconvinced, because something crucial is being left out — the strong, negative feelings such resistant patients can arouse in caregivers.

Emotions and the difficult patient

Anorexia nervosa is a prototype of the "difficult illness." Silverman[24] described anorexic patients as "irascible, manipulating patients [who] plague concerned physicians"; strong-willed and compulsive, they exhibit "overwhelming envy, greed, selfishness [and] narcissism." Bruch[25] described them as "deceitful and cunning," and Garfinkel and Garner[26] characterized them as "resistant and deceitful." In short, many anorexic patients are unpleasant and demanding. The intractable cases especially can make physicians and staff feel helpless.[27] Such feelings have significant implications for how patients with anorexia are treated.

The ethical analysis so far has suggested that no further feedings were provided for this anorexic patient because of a judgement that such treatment was futile. When treatment promises no medical benefit it need not be offered.[28] Our worry is that an analysis of futility that uses only abstractions such as benefit and burden may simply be a *post-facto* rationalization of the strong negative feelings such patients evoke in others.

What is most troubling here, then, is the concern that treatment was withheld because the patient was so difficult.[29] All those involved in her care had to cope at some stage with their own feelings of guilt at finding her burdensome and actually or potentially exposing her to danger and eventual death. This guilt was a real strain on those who tried to carry out the treatment policy of keeping her in the community. When the patient was not in hospital residents and staff at the family practice clinic frequently had to deal with her calls for help and her refusals of treatment. When she was in hospital and in restraints enormous resources, especially nursing ones, were invested in her care.

Repeatedly reviving patients who consistently wish to die is not a pleasant task. It can be time-consuming and frustrating and can make healers feel helpless.[30] Such "heartsink" patients, like black holes, endlessly suck up emotional energy from caregivers.[31,32] This unpleasantness raises the emotional stakes of treatment decisions for everyone involved.

This deeper, distressing emotional reality is often not considered in abstract ethical analyses of decisions to limit treatment.[33-35] The third primary principle of bioethics, justice, suggests that we need to consider how others are affected by a medical decision to limit treatment. This usually means considering whether the monetary expense of a proposed treatment for the hopelessly ill patient is worth while.[36] Monetary considerations were not relevant in this case, but emotional ones were. These costs are less easy to formalize but can be very real in the clinical context. Unless acknowledged they may unconsciously affect decisions to limit treatment.

Although this anorexic patient almost certainly could not have been saved, judgements about the best interests of patients like her are far from simple or straightforward. At least, it might be said, those involved with this patient achieved a consensus concerning her final treatment. Certainly this gives some hope that the decision was not subjective. But popularity is not the same as truth,[37] and consensus may be achieved at the expense of honestly acknowledging the difficult feelings aroused by the hopeless case. Members of the families of such patients and the treatment team alike may have an interest in not considering these emotions.

This is not to say that such feelings are irrational or illegitimate. Patients can be extremely burdensome, and caregivers are not required to sacrifice themselves to save someone who is unlikely to be saved anyway. By exploring strong emotional reactions to others we enlarge the ethical sphere by becoming aware of the conditions and needs of others at a deeper and more inclusive level.[38] Although fraught with difficulty such exploration is better than having these feelings unconsciously influence important medical decisions.

This case has implications for other difficult

patients — for example, those with various personality disorders, self-abusing patients and those with chronic intractable and irreversible illnesses such as advanced dementia and acquired immunodeficiency syndrome. Behind the judgements of futility and therapeutic nihilism by family and staff may lie a desire not to be involved with these patients. Medicine has recognized that one may be overzealous in wanting to save the inevitably dying. But the obverse side to this is withdrawal from patients who are incurable or recalcitrant. The danger is that irreversible decisions to limit treatment will be made on the basis of unconscious feelings. This hazard can never be eliminated from our decision-making, because we will probably always have emotional "blind spots." However, to make our judgements as inclusive as possible the strong emotional reactions of caregivers to patients need to be acknowledged and explored.

Conclusion

Forced feeding in anorexia nervosa is usually appropriate if patients are in danger of imminent death by inanition, but when a life of suffering is sustained only by more and more aggressive measures it may be appropriate to withdraw life-saving nutritional support. However, before this is done there must be due consideration of the strong feelings elicited by caring for mortally ill, burdensome patients.

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